

Supplemental Digital Content 1: Senior Center Focus Group Guide

OPENING QUESTION

I'd like to talk about making difficult medical decisions. When people are very ill, it is hard to know what the best treatment is. For example, a medicine may help someone to avoid blood clots, but it might also cause them to have bleeding. We often call this a trade-off. We know that people have their own opinions about what trade-offs are acceptable or worth it to them.

I'd like to hear about a trade-off you have faced when making a medical decision for yourself. Please describe for me a medical choice that you had to make where there were trade-offs. Please do not use any names or personally identifiable information.

PROBE: (If limited response) For example, a treatment that would help one thing and cause problems with something else?

PROBE: Does anyone else have another example?

KEY QUESTION #1a

Trade-offs in medical decisions can be very serious, especially when people are elderly and frail. Sometimes people face an extremely difficult choice. On the one hand, they could opt for treatments like surgery or chemotherapy that have a lot of side effects and complications but that have the potential to extend their life. On the other hand, they could decide to go without such treatments knowing they might not live as long without them.

I am now going to describe a very difficult decision that is based on a true story from our hospital. We would like you to imagine that you are either the patient or her son or daughter and that you need to make a decision about having surgery.

Ellie Williams is a frail elderly woman with many medical problems including breathing troubles and heart failure. Today, she comes to the emergency room with her daughter because Ellie has suddenly had serious pain in her chest and belly. Ellie's doctor tells her this pain is from a large aneurysm in her chest and belly. It is an enlarged blood vessel that is likely to rupture, or burst, in the next day or so and this would lead to her death. The treatment for the aneurysm is a very big surgery that would likely have many serious complications. Ellie is 79 years old. She and her family need to decide whether surgery is "worth it" for her within the next hour or two.

QUESTION: Tell me about the kinds of things you would want to know about Ellie's choices in order to make the right decision for her or someone like her that you love.

PROBE: What else would you like to know about the treatment options?

PROBE: Unfortunately, this is a very difficult choice and there is no ideal option. What would you want to know about the surgery in order to decide if it is "worth it"?

KEY QUESTION #1b

Now, think about yourself facing the same situation as Ellie. Imagine that you were in the emergency room and that you were told you have an aneurysm, which may rupture in a day or so and that this may cause your death. The treatment for the aneurysm is a big surgery that would probably have many serious complications.

QUESTION: Please tell me how you would decide whether surgery is right for you.

PROBE: What would you need to know in order to make this decision about this surgery for yourself?

VIDEO

Next, I'd like to show you a video. The video is about 7 minutes long. It shows a surgeon giving Ellie and her family information and trying to help them decide what to do. In the video, the surgeon will use a decision aid. We'd like you to watch the video and then we will ask some questions about the decision aid that the surgeon uses.

Please keep in mind that the people in this video are actors and the scenario you will watch is just a short segment of what Ellie will experience during her visit to the emergency room. Unfortunately, we do not have time to show you what occurred before or after Ellie's conversation with the surgeon. In addition, we have deliberately asked the actors to speak plainly and without emotion so that you can pay most attention to the information that the surgeon is presenting, rather than how he acts towards Ellie and her family.

In the video, you'll notice that the surgeon shows Ellie a diagram on a sheet of paper. I'd like to give you a copy of this diagram so that you can see more closely what the surgeon is referring to.

[Transcript of video available in Appendix 2]

KEY QUESTION #2a

Now I have some questions about what you saw in the video. First, I want to note again that the interaction you saw in the video between Ellie and the surgeon is not the only interaction they will have. Later the surgeon will come back to see her and to find out her personal feelings about each choice in order to help her make a decision. For now, we wanted to present just a brief part of their interaction in order to focus on the decision aid that the surgeon used to talk with Ellie about her choice.

Ellie's choice is indeed a difficult one, because neither the surgery nor the supportive care that the surgeon described is ideal. Remember, this was based on a true story from the UW hospital when there were no treatment options other than surgery or supportive care.

Okay, now let's talk about the decision aid that the surgeon used to talk with Ellie about her options. Please keep in mind that "decision aid," as we're using this term here today, refers not only to the diagram on the sheet of paper but also to the information the surgeon provided Ellie.

First, let's talk about the information the surgeon provided using the decision aid. Do you think Ellie was given too much information? If so, what information was too much?

Was anything missing from the information that the surgeon gave to Ellie? If so, what was that?

KEY QUESTION #2b

In what ways will the decision aid used by the surgeon in the video help Ellie choose between surgery and supportive care?

In what ways will the decision aid used by the surgeon in the video fall short of helping Ellie choose between surgery and supportive care?

KEY QUESTION #2c

In what ways will the decision aid used by the surgeon help Ellie make a decision based on what is important to her?

In what ways will the decision aid used by the surgeon fall short of helping Ellie make a decision based on what is important to her?

KEY QUESTION #2d

In what ways will the decision aid help the surgeon assist Ellie with her decision?

In what ways will the decision aid make it more difficult for the surgeon to help Ellie decide between surgery and supportive care?

PROBE: In what ways is the decision aid useful for the surgeon? In what ways is this decision aid not useful for the surgeon?

KEY QUESTION #2e

For this next question, let's go around the table again one by one: Do you think the surgeon in the video wanted Ellie to choose one course of action over the other or do you think the surgeon was neutral about Ellie's choice?

IF SURGEON WANTED ONE COURSE:

- Which choice do you think the surgeon wanted Ellie to make?
- What made you think the surgeon wanted Ellie to choose that?

IF SURGEON NEUTRAL:

- What made you think the surgeon was neutral about Ellie's choice?
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ENDING QUESTION #1

You have helped us a great deal today by sharing your thoughts and opinions about how to improve the decision aid that the surgeon used with Ellie in the video. Is there anything else that you would like to add to what you said already on how to improve the decision aid in the video?

ENDING QUESTION #2

We've covered a lot of ground this evening. Before we close, is there anything that we didn't ask you about that we should have?

CLOSING AND EXIT SURVEY

Thank you very much for coming and sharing your ideas and experiences with us today. Before you leave, we'd like to invite you to fill out a very brief questionnaire. Your responses to the questionnaire are important to us. And, like everything that we talked about today, your responses to the questionnaire are confidential and voluntary and will be used only for research purposes.